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Fulfilling a sense of duty: how men and women giving care to spouses with multiple sclerosis interpret this role

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ABSTRACT *This qualitative study examines how spouses experience caregiving when predominantly motivated by a sense of duty and addresses whether any differences between female and male caregivers can be detected. For our purpose semi-structured interviews were conducted with eight male and five female caregivers providing total care to their spouses who are disabled as a result of multiple sclerosis (MS). The analysis consisted of fragmenting and connecting the data and involved close reading and constant comparison. Participants involved in this study maintain caregiving despite the unfavourable changes they have noticed in their relationships. They interpret caregiving as something they just have to do. Males and females develop different perspectives on caregiving, which are illustrated by two exemplary case stories that can be summarized respectively in the phrase 'You have to be satisfied with it', and as 'I have to become harder and less self-sacrificing'. Explanations for these outcomes are sought in differences in moral orientations between women and men and in gender differences regarding their feelings of duty and rights. The results shed light on previous findings that female caregivers report more stress than male caregivers and as such pertain on the discussion on home health care.*

KEY WORDS *Chronic illness; coping; gender differences; disability; spouse; caregiving*

RESUMEN *Esta investigación cualitativa estudia como los cónyuges experimentan (como lo viven, que sienten) el cuidar cuando lo hacen sobre todo desde un sentido del deber. También toma en consideración la pregunta de si hay diferencias entre mujeres y hombres. Para esta tarea se hicieron entrevistas semi estructuradas con 8 voluntarios masculinos y 5 femeninos que cuidaban a sus respectivos cónyuges, los cuales sufrían limitaciones a causa de la esclerosis múltiple. El análisis consistió en fragmentar y conectar los datos e implicó leerlos minuciosamente y compararlos constantemente. Los participantes en el estudio siguen cuidando de sus*

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cónyuges a pesar de los cambios negativos que sufren en su relación. Lo consideran como un deber. Hombres y mujeres desarrollan diferentes perspectivas sobre cuidar, que se ilustran con 2 case stories que pueden ser resumidos como respectivos 'Tienes que asumirlo y ser feliz con ello' y 'Tengo que ser mas fuerte y sacrificarme menos'. Explicaciones a estos resultados se buscan en las diferencias entre las orientaciones morales de hombres y mujeres y en las diferencias entre sus sentidos del derecho y el deber. Estos resultados aclaran resultados anteriores que afirman que voluntarias féminas experimentan mas estrés que voluntarios masculinos y es por esto que se relaciona con la discusión sobre asistencia domiciliaria.

Introduction

When one of the partners in a marriage becomes disabled or chronically ill, spouses often start caregiving (Blaxter, 1976; Kuijer, 2000; Lyke, 2000; Parker, 1993). Parker (1993) speaks of the invisible marriage between disability and giving care. She argues that since there are few other relatives involved in caregiving and the professional support for chronically ill, in particular for young disabled adults, is inadequate, it is almost inevitable for spouses to become caregivers. Previous research showed that the unpaid caregiving of family members can be and often is burdensome (Duijnste, 1991; Kuyper, 1993; Lewis & Meredith, 1988). When caregiving has a long duration and when 'total' care is needed it is particularly burdensome. Graham's description of family caregiving as a *labour of love* fits this finding excellently, since it expresses the duality between the affection that is supposed to underlie the act of informal caregiving and its labour-intensive nature (Graham, 1983).

Literature in general suggests that women who care for a person with a chronic illness are even more burdened by their caregiving than men and that they report a more dramatic effect on their health and well-being than their male counterparts (Barusch & Spaid, 1989; DeVries *et al.*, 1997; Robinson, 1988). Gender differences in caregiving have been the focus of some prior studies. Parker (1993), in her original study into young couples in which one of the partners was disabled, found that women have more difficulty than men in putting their own needs first. Despite gaining increasing control over aspects of the couple's life together, in particular females sometimes lose power in relationships if their partner's disability becomes the main focus of their lives together (Parker, 1993). Disabled women see what their husbands do for them in terms of providing personal care and domestic services and tend to feel guilty and sad about the effects of their illness on their husbands' lives. Disabled men on the contrary, may not notice what their wives do when they take on responsibility for their care after the onset of a chronic illness, because they expect them to provide them with some aspects of personal care (Oliver, 1983; Parker, 1993).

Miller (1990), who examined partners who gave care to their spouses with dementia, reported that female caregivers – more than male caregivers – were attentive to their spouses' needs and subordinated their own plans to those of their spouses. Male caregivers were more in control and better able to distance themselves emotionally by focussing on tending instead of on the effects that the

illness had on their former and actual relationship with their wives. This corresponds with the results of Twigg and Atkin (1994), who typified the responses of some female caregivers to their caregiving role as engulfment. On the other hand, male caregivers were more capable of setting boundaries and balancing their own interests with those of the person they supported. All of these complex mechanisms seem to be responsible for differences detected in reactions and effects of caregiving between both sexes.

In community nursing and housekeeping services in The Netherlands the model of 'carers as co-workers' is paramount (Lyke, 2000). The primary aim of professional help remains providing high-quality care for the cared-for person whilst acknowledging the caregiver's interest and well-being but essentially on an instrumental basis (Twigg & Atkin, 1994). This means that family and friends are automatically transformed into informal caregivers when a family member or friend needs help to go about his or her daily life. Previous studies showed that services were provided along gendered lines and that female caregivers received less professional help than male caregivers (Bywaters & Harris, 1998; Parker, 1993; Twigg & Atkin, 1994). As a consequence, home care was thought to be oppressive in particular for women and to a lesser extent for male spouses; some people even supported the concept of residential care for disabled people (for a discussion, see Morris 1993a). Others (i.e., Parker 1993; Morris, 1993a) rejected this idea since they pointed at what in their eyes was the real issue, namely the support of disabled people and not the needs of caregivers. People with disabilities should be able to contract and maintain personal and family relationships, but these should not become the basis of caregiving.

Caregiving is a challenge for the marital relationship (Lyons & Mead, 1995; Robinson, 1988; Thompson & Pitts, 1992). Spouse caregivers seem to live up strongly to the marriage vows and the responsibilities that being married entails. This can result in partners staying together because of felt obligations and pressure to give care just for the sake of marriage (Morris, 1993b; Oliver, 1983; Parker, 1993). The objective of this study is to ascertain in what way the group of caregivers who seem to be fulfilling a sense of duty attaches meaning to their caregiving role and how they act upon this meaning accordingly. The study also considers whether men and women in this group respond differently to the demands of the caregiver role. It was felt that this could clarify the differences between men and women in meeting the challenges that are imposed on them by disability and the perceived burden ensuing from it. The gender socialization framework offers an explanation for any possible differences by assuming that women have been socialized to have a stronger commitment to caregiving than men, especially in terms of sensitivity to interpersonal elements (Gilligan, 1982; Miller, 1990). In the final section we will discuss this explanation in greater detail.

The selection of spouses looking after their partners who have MS, offers the opportunity to study caregiving in a situation in which the challenges of caregiving in the context of marriage are evident and maximised (Morse, 1999).

Partners of persons who have MS are known to be experiencing a heavy physical and psychological burden (Bartels DesRosier *et al.*, 1992; Duijnste & Boeije, 1998; Gulick, 1995; O'Brien, 1993). Multiple sclerosis (MS) is a severe neurological disease. The course of MS is unpredictable and can lead to numerous and variable symptoms, including impaired mobility, weakness, sexual dysfunction, difficulty in communication, blurred vision and loss of control over bowel and bladder function (Zwanikken, 1997). MS primarily affects young adults most commonly in the 18–40 age group and two to three times as many females as males (Zwanikken, 1997). The long duration of the illness implies that family members who are providing care to their relatives at home, do so over a long time. This inevitably makes considerable demands on their endurance and coping capabilities (Boeije *et al.*, 2003). In The Netherlands, an estimated 15,000 people have MS, around 4,000 of whom live at home while they are disabled and in need of help with their personal care (Dutch Multiple Sclerosis Society, 1997).

Research methods

Theoretical orientation

An interpretative methodology applied to the subject, as Banyard and Graham-Bermann (1993) suggest, more accurately reflects the experiences of diverse groups, including female and male caregivers, than the current research paradigms of coping with stress. In general, they feel that current research, which predominantly has a quantitative character, uses a narrow focus on gender, misses the issue of power and influence of family members on individual coping attempts and uses too confined outcome measures. Researchers guided by an interpretive orientation can overcome some of these limitations because, when adopting qualitative methods, they can ask for explanations, they use flexible methods to grasp the complexity of a phenomenon and they can look for the variety between groups with concern to their family relationships and gender roles.

The interpretive stance taken here is symbolic interactionism. The basic premise is that human beings act towards things on the basis of the meanings that the things have for them. The meaning of things is derived from and modified through the social interaction that one has with one's fellows (Flick, 1998). Qualitative research methods are chosen then, since meaning and the motivations behind behaviour cannot be understood from a disengaged point of view or without taking the context into account.

Procedure

Eight men and five women who provided the direct and ongoing personal care and assistance to their spouses were interviewed for this study. All were living with their spouses in The Netherlands or in Belgium. Access to the participants

was gained through home care organizations and members of the advisory committee installed at the start of the project. The project had a timescale of 2 years. All recruiters had various connections with MS, some as MS patients or caregivers themselves and others, such as a neurologist, nurse, and committee member of the National Organisation of Caregivers and the Dutch Multiple Sclerosis Society, as professionals. They asked the persons who had MS to participate, as well as the persons whom they designated as the primary caregiver. The recruiters were instructed to include people who differed in various respects, for example in perceived burden, years of 'service' or in communication between the partners.

Study participants

The caregivers (eight men and five women) ranged in age from 48 to 75 years, with a mean age of 60. Husbands providing care were older (mean age = 60.8) than female caregivers (mean age = 57.4). Five had been manual workers (chauffeur, repairman, etc). Three were professionals (teacher, manager, estate agent). Three of the women were housekeepers. Two males had academic qualifications. At this stage, three men and one woman were retired. Two men had changed their full-time jobs for part-time jobs to spend more time at home. One man and one woman had stopped working in order to provide care at home. One man was working full-time and one man was registered as disabled.

The men who are ill have known on average for 25 years that they have MS. The disabled women have known this for about 13 years. Being diagnosed with MS can be quite arbitrary, since it is sometimes diagnosed after years of health problems or not revealed right away. Despite the difference, the groups of caregivers are comparable in terms of years they have provided more serious support and in the help they provide at the time of study. Disabled persons of both groups need help or supervision with an average of five activities of a total of six possible Activities of Daily Living (ADLs: bathing, dressing, transfer, toileting, continence care and feeding). All disabled persons are unable to walk and use a wheelchair. This information is described in the Appendix.

Four male caregivers thought their health was good and reported no disabling conditions. One man was recovering from a broken hip, one had problems with his knees, one had heart disease and one complained of pain in the shoulder and arm. Four female caregivers mention periods of depression, tiredness or nervousness; sometimes combined with pain in the back and complaints in shoulders and arms. Only one woman had no remarks about her health. Twelve families received help from district nurses and nine from housekeeping services. Only one couple did not receive any professional help.

The participants who have MS were on average 58 years old. The youngest was 44 and the eldest 69. None of them were employed outside the home. Five women had been housekeepers, three men and two women had been forced to stop working because of MS and two men and one woman were retired.

Formerly, six had manual jobs (shop assistant, textile worker, etc.) and two were professionals (teacher, physiotherapist). Twelve families had children and, in four cases, one or more of the children still lived at home.

Data collection

Qualitative interviewing was used to gain access to the participants' personal stories. Each participant was interviewed once. The interviews were tape-recorded and transcribed which resulted in approximately 170 pages of text for the 13 caregivers alone. Interviews took on average 45 min with a range of 30–90 min. Directly after the interview a contact summary sheet was made, on which the most important themes in the interview, the social-demographic data, some features of the interview situation, as well as reflections on the interviewer's roles were noted (Miles & Huberman, 1984). The interviews were conducted by two female interviewers in their early 30s. One interviewer [HB], a sociologist, conducted the first interviews with nine caregivers and their spouses. The second woman, a nurse and sociologist, who interviewed the remaining four couples, read every previous interview and used the same list of topics. This obviously 'socialised' her to conduct interviews in the same way, which resulted in few inter-observer variations.

When we started, we had selected a number of topics for the semi-structured interviews derived from literature as well as from our own expertise. The participants were asked how they saw their caregiving role and how caregiving had changed their lives. Their motivation to continue caregiving, their doubts and problems were also dealt with in the questions. There were questions pertaining to their resources in order to discuss what or who could strengthen them and replenish their energy once they felt they could not go on. After each interview, additional topics for the subsequent interviews were formulated. These concerned such topics as how they saw their relationship challenges and how they valued their spouse's coping attempts.

The interviews with the caregivers were compared with the interviews of their spouses for the sake of data triangulation (Kimchi *et al.*, 1991). We report elsewhere on the experiences of the disabled persons as a result of MS (Boeije *et al.*, 2002). The interviews with the spouses were conducted with a view to obtain additional information on the perspective of the caregivers. The disabled spouses sometimes gave different examples than the caregivers and touched on themes that placed the caregivers' experiences in a broader context. For instance, Mr and Mrs D talked about the same event, namely a physiotherapist visiting their home to look at the chair in the shower that is used by Mr D. He mentioned that his wife usually notices any deterioration in him before he does. His wife made clear that she tries to hold on to the former situation because she does not accept the deterioration. By adding his information to her story we gained a deeper understanding of how she dealt with the progress of the illness in the context of the adaptation process of the family as a whole.

Analysis

The text was then analysed using a constant comparative analysis (Strauss & Corbin, 1998). This analysis was made up of two activities that keep each other in equilibrium, namely fragmenting and connecting (Dey, 1993). In the first activity, the component parts of each interview were separated out. This involved close reading and line-by-line analysis. The process of code-and-retrieve was conducted using the WinMAX computer program for qualitative analysis (Kuckartz, 1998). This resulted in a number of areas that we felt needed to be described, such as 'changes in the relationship', 'inevitability of caregiving', 'enduring' and 'setting limits'.

The second activity in the analysis process consisted of interpreting the parts as a whole and connecting the pieces together. An interpretive reading of the interviews was conducted, which called for our active involvement in inferring meaning from the data (Mason, 1996). Both researchers brought different backgrounds to the study, namely sociology and health care policy and management, which allowed the data to be interpreted from different angles and constituted researcher triangulation (Kimchi *et al.*, 1991). In analysing the interview material in the original sample of 21 spouse caregivers, two related, core areas emerged. One was the caregiver's relationship with the ill spouse and the other area of analysis was the main motivation to continue caregiving. A study of these areas showed that participants were identified as being inspired mainly by love and involvement (8 interviews) or by duty and the promises made to give care to one another (13 interviews).

Since we were interested in caregiving from a sense of duty, the focus was on these last-mentioned interviewees. The main line of these 13 interviews was summarized. Within this common framework, it struck us that the caregivers had different ways of thinking about and dealing with what they perceived as their plight to provide care. The search for differences and similarities produced two variations within the main line: one report is of sacrifice and guilt, whereas the emphasis of the other is on doing the right thing. This pattern in the study group was gender-related. To gain a sense of the distinction it was necessary to focus on the case stories as a whole. A matrix was used to compare information across men and women in terms of the themes in the study (Miles & Huberman, 1984).

In rendering the situation of the caregivers in our study sample understandable, the narrative stance of the writer is that of reporter and interpreter of the caregiver's perspective (Sandelowski, 1998). In order not to confuse both stances we mark the distinction by a change in paragraph or by insertion of us as writers. The data extracts that are presented either in paraphrases or quotes were selected to document the experience of caregiving from a sense of duty and to offer the possibility of control. Quoting is also done to provide the reader with a feeling of the struggles people are going through and to make the different perspectives that people develop of their caregiving understandable. The case stories are assembled in order to establish the participants' own interpretations of their lives with regard to the caregiving experience.

A duty to continue caregiving

In the main line of the selected interviews with caregivers, references are made to two crucial themes that underlie their responses to caregiving. Firstly, the changes in the marital relationship that they experience and mostly view as unfavourable. Secondly, the expressions they use to describe the reasons why they started to provide care and in particular why they continue to do so. As there already is some excellent work on both these subjects (e.g., Morris, 1993b; Parker, 1993; Twigg & Atkin, 1994), it is not our aim to give a full description of the developments in the relationship and in the caregivers' motivations. The data presented here serve to demonstrate that in the study sample the balance between feelings of obligation and affection turns out to be in favour of the first.

The changed relationship

Most caregivers point out that their relationship has been an average one. They had raised a family together, shared interests like travelling and had social activities like family birthdays that they attended together. Yet, they also characterized their marriage as one in which both partners had their own tasks and led their own lives. Most of the times this meant that the husband had a full-time paid job and the wife had domestic tasks and raised the children (eight families) that she sometimes combined with a part-time job (five families). Two caregivers in our sample described their marriage before the onset of the disease as not a strong one. For instance, Mrs T who indicates that her husband was spoiled by his mother, always wanted things done his way. Mr S told us that his wife had had a very harsh upbringing and was already not much fun to live with.

When MS progressed and a more intensive caregiving was needed, the caregivers decreased their working-hours or stopped working altogether to give care at home and their spouses stopped working because of MS. They had to spend more hours together which put unquestionable pressure on their relationship: 'Before, we both worked and I was away from home a lot for my job. My wife was an independent person. Now, we live on top of one another all day. I am at home more and my wife is more dependent on me, and that contributes to conflicts and tensions' (Mr K).

Two male caregivers mention that they cannot communicate with their wives anymore like they used to do, because their wives' mental capacities have in their eyes been affected by MS. They feel they cannot consult them as equals as they did before. Four others remark that MS has robbed their spouses of their hobbies and general interests, which has turned them into less companionable and less equal partners:

As partners we are growing apart since we lead our own lives more and more. Some things are just physically impossible, like biking together. She sleeps a lot. She is indoors more and her world is shrinking. So she sees many things through a magnifying glass, she blows things out of

proportion, for instance with the children. She is not being reasonable. And I do understand that. When you see that everything slips through your fingers, it is quite normal to be emotional about that. (Mr C)

Together with the caregiving part that was introduced into the relationship with MS progressing, the caregivers signal that their relationship has become a more distanced one:

Yes, our relationship has changed. It has become more distanced I think. It is more a care-based relationship now. And that is quite another matter. Yes, that has changed. Like I say, things are more detached. She is more a person you have to take care for, and that is different from what it was. She has become a patient and a partner is not at all like a patient. (Mr V)

Still others notice that the spouses' bad days influence their own moods and their relationship:

We have had two rough years. This is the first year after our house was completely adapted and we are more at ease now. It was very heavy. I am the type of person who is not capable of cheering someone up, I am the type of person who gets carried away by it. So when he was grumpy, which he often was, I could not withdraw from it and I got gloomy too. And when he is cheerful and I can notice when he is, than I am doing fine too. (Mrs B)

Nine caregivers think that their partners did not accept their illness at all and are thus coping with MS in a way that is rather hard to deal with. They point at spouses who cannot deal with having to give up work, who are depressed, who do not want to talk about MS or who want to control their situation and command everyone around them. Not all caregivers respect this behaviour and they blame their spouses for reacting in this way which further propels the relationship in a downward spiral.

These changes, amongst others, have according to the caregivers eroded the relationship with regard to some of its worthwhile aspects. Often the caregivers remark that their partner has changed as a person and that his or her physical and sometimes mental capacities are affected. MS, they feel, has changed the person they loved and chose to marry and in a way changed them and their relationship too. They regret the loss of their partner as an equal companion with whom they exchanged ideas and support. Although according to them the quality of the marriage has diminished they remain together for other reasons which are the subject of the next section.

Starting and maintaining caregiving

Most caregivers we spoke to have gradually grown into the caregiving role. Some had taken on caregiving as a matter of course and had taken it for granted as

part of their marriage. As some say 'It crosses your path' or 'I never had any doubt about it'. By and large, they had no doubts whatsoever to start caregiving. As Mr L says: 'Nobody asks whether you want to provide care or not. It is just something that is there. It has to be done and it was thrown upon me'. Several caregivers saw themselves drifting into the caregiving process with the progressive nature of MS, and saw dark clouds gathering when tasks accumulated and they had to give up their own activities and for instance their jobs. At this moment they all experience all-encompassing demands on their time and attention. Some call it a full-time job, others say 'I'm 24 hours stand by'. Some caregivers who managed to keep a paid job speak of the second shift when they come home to their spouses.

As a rule the feeling of inevitability has taken root in caregivers. Inevitability is related to the expectations and experiences with professional home care. With the exception of one couple, all families receive help from district nurses and/or housekeeping services. Most families have approximately nine different professionals coming over to their houses and in the holiday months they meet many new and sometimes inexperienced helpers. With MS progressing, they needed more help over time and in the phase of total care support (alterations to the home, aids, home help, community nursing) is extensive or maximal. The needs assessment takes into account the care given by the spouse and other family members. In general, families are satisfied with the help they get and notify that they 'cannot do without them'. However, the families believe that professional home care is in no way capable of providing all the care that is needed. Their organizations allow professionals to come at certain times of the day, whereas some of the disabled persons need help unexpectedly, others need help the whole day through and most of them even at night. So that is were spouses inevitably come in, or so they feel.

In answering why they maintain caregiving, several spouses pointed out their belief in marriage and in the vows they have taken. They have promised to take care of each other and they support this notion. They see their spouse's illness as something from which there is no escape and their caregiving is also perceived as inevitably caused by the promises made. 'Till death, well, that is the vow of marriage. And I intend to keep that promise although it is hard at times'. Another caregiver says that he is from a generation that keeps their promise, while he expects many young people to divorce should they meet what he has met. It is here that they come to speak of fulfilling a duty. As Mr S says: 'It is a duty, cause the love was soon gone'.

Reciprocity in the relationship is an important motivation for some to continue caregiving. The same Mr S mentions his appreciation for his wife who took over their business when he was ill, now he returns the favour although he depicts his relationship as very problematic. Mr R admired his wife who took care of the children in an excellent way and now he gives her the care she needs. Others are motivated by an idea of virtual reciprocity: if they had become ill, their partner would have taken care of them instead. As Mr C expresses these general feelings:

You have lived so many years together, done things together, worked together, and then to say when things are not going too well, look after yourself, that is something I think is frankly indecent. And I take into account that when something like this hits you, you expect the other party to do right by you. Consider it might be you who is sitting in that wheelchair and it afflicts you, it might just as well have been you.

The motive that stands out to remain with the spouse and provide them with personal assistance is to prevent them from being admitted to a nursing home. They have promised their spouses to do whatever is possible so that they can stay at home. Caregivers are committed to this promise and they are kept to it by their spouses. As a consequence, they view home care as complementary to their own help, which means that they are involved in total care to prevent a placement.

At this stage, a number of characteristics of caregivers' stories are noted. In general, there were almost no expressions of love and affection in the interviews with caregivers. The participants present themselves as moral persons who act according to what crosses their paths and who are loyal to their partners, despite their relationships which are characterised by disagreement and detachment. This gives way to an obligation with a strong reference to the marriage vows. They consider the provision of total care as part of the deal since they took the vows; conversely, they realize they are going beyond normal expectations.

Two perspectives on caregiving as an obligation

In the main line described above, two variants were discovered. In this section we present two case stories of caregivers who represent these variants. The areas mentioned in the above section – changes in relationship, inevitability, reciprocity and preventing an admission – are used as a framework to portrait both variants. Each portrait is labelled with the motto that the person uses to summarize his or her response to caregiving: *You have to be satisfied with it* and *I have to become harder and less self-sacrificing*. The first pattern is a response which is typical of the male participants in our study group and the second pattern is held by female partners in the study group. Later on we will examine two cases that seemed to go against this trend.

You have to be satisfied with it: the story of Mr J

Yes, sometimes friends ask me how things are sexually. I say you put that aside, there's nothing more you can do about it. They ask me, are you satisfied with that? I say you have to be satisfied with it. Sometimes we have problems, but she's easy going. So you help each other and you take things as they come. If you want to be dramatic about it, well, you promised to be loyal to each other, so you want to hang on as long as possible, to the end if you can.

Relationship. Here is the case of Mr J. He is a man in his 50s whose wife has had MS for 15 years and is severely disabled. It was difficult for Mr J at first, both because he had to get accustomed to a lot of new activities and because he and his spouse could not talk about the situation together. Finding out what his wife could do on her own and which tasks she needed help with was unpredictable because it differed from day to day, depending on how the MS behaved. He then began to doubt his ability to go on and he thought about leaving her. As the years passed, it became clear which tasks his wife could not do anymore and which ones he had to take over. They had also learned to talk about these matters, which reduced the tension between them.

Mr J believes that the changes in his relationship have led to a form of separation. He now looks to the future, hoping that when his wife dies he will still have some good years left. He is what Lindgren (1993) terms 'concentrated' on the exit stage, a time when he will not have to give care anymore:

That is how I've been able to give it a place in my life. And then I always say, who knows whether it will last ten more years, who knows, five more, who knows, it may only last two more years. Well in that case, I'll be sixty, and I'll still be able to do the things that I can't do now. I am prepared for that. I've sorted everything out financially and now I'm planning to look for other accommodation. Then I want to be my real self again, really, and not always be under pressure.

Mr J's wife can be recalcitrant and criticizes what is being done for her by him and by professional care providers. He tries to take little notice of such difficulties and glosses over his partner's behaviour as an understandable response to the illness.

Inevitability. Mr J accepts his wife's illness as a fact. It is just something that is there and he is pretty much resigned to it. He does what he thinks he ought to do; namely give care to his wife. He refers to the promise he has made when he married her. Accordingly, he has taken up the role of caregiver and tends not to complain about it. When his wife dies he will not feel regret or guilt because he will have done his best.

Round-the-clock caring is a heavy task. Mr J sees no alternative to taking care of his wife to the end, but to him this does not mean he has to do everything for her. Some tasks are left to others. In the morning Mrs J receives help from a district nurse and she has help from housekeeping services twice a week. His wife has no objections when someone else provides her with personal assistance. Mr J has set limits to his caregiving. He has decided that he does not want to clean his wife after she has been incontinent. This task gives him a feeling of inferiority and is just too much for him to cope with. Nevertheless, Mr J despite having problems with his knees cannot give in to physical complaints because he would not know who else to turn to for the provision of extra home care.

Reciprocity. Although Mr J derives some satisfaction from doing his duty, he acknowledges the losses that it has brought. At times he finds it difficult and feels that he has given up a lot:

I have a busy life, because I'm constantly engaged in tasks. I help whenever I can. Fortunately, in the mornings I receive help. Had this not been the case, I would not know how to deal with everything. I trust that there is help for us. If everything rested on my shoulders then I don't think I could carry on. Well, in the afternoon I am always busy with her, giving her something to drink, making dinner. Holidays are not for us, because we have nowhere to go. If you want to go somewhere there is so much money involved, you have no nursing help. No, it is always so much more expensive, you always need aids or special adaptations.

He protects himself from becoming overwhelmed by the situation. He knows that staying in the house all day does him no good. He has many acquaintances who regularly ask him how he and his wife are doing. He rides his bicycle, sees friends and plays pool. The four children live near by and one of them visits them every day. He sometimes tells his general practitioner how he is doing and he lets off steam watching sports on television.

Prevent an admission to a nursing home. Mr J has promised his wife to give care to her and they agreed that she does not have to live in a nursing home. Mrs J does not want to live anymore when either she is unable to use her voice or when her mental deterioration reaches the point where she cannot stay at home any longer. Until that time Mr J will take care of her and he has a clear idea of what he will and will not do. When he thinks that certain jobs are physically too heavy or too time-consuming, he will ask someone else to take over these tasks.

I have to become harder and less self-sacrificing: the story of Mrs T

I knew my husband was ill when we married. Only, I was twenty years old and I did not give it a thought. Nowadays I often think, if I had known I would not have done it. What I find very hard is that when I stopped working altogether two years ago I lost contact with the world and social contact with colleagues and customers. Now, how shall I put it, after all those years there is no ... , then you think you have to go on although it is very hard from time to time.

Relationship. This is Mrs T talking. She is in her late 40s and her husband has had MS for almost 30 years and now needs help with everything. At first, her husband's illness did not interfere with their normal lives. Her situation only really became difficult when her husband became more severely incapacitated. When she was away at work he fell from his chair and she felt responsible to be

at home more. She gave up her paid job to give care to him. Moreover, her husband disliked the idea of having professional care providers around and Mrs T provided all the personal assistance herself. He brought pressure on her to provide him with what he wanted. Her general practitioner once stood up to her husband and defended her choice to sleep in separate rooms so that she could have an undisturbed night's rest.

At this moment she is mostly bothered with her husband's behaviour and with the relationship problems. In her eyes her husband cannot come to terms with his disability. She says that he has become a little easier to deal with now and that he is more compliant and less ready to criticize her and order her about:

He adapts more easily than he used to. In the beginning he was more selfish. When I didn't get him out of bed fast enough he would beat on the wall with his urine bottle. Now he has himself in hand more and everything I do is all right with him. His character has changed for the better compared to when he was more negative. I cook good meals for him, I always do, but he never says so. He can't say it. If he would only once tell me that I take good care of him, only once a month or so, but he just won't.

Mrs T's relationship is burdened by all these difficulties. She takes her husband's reaction personally and is negatively affected by it. She cannot remember an occasion of intimacy and therefore feels she is his nurse rather than his wife. She even bottles up her own emotions because feelings of guilt and being fed up with MS cannot be discussed.

Inevitability. Mrs T is convinced that her husband's illness is the worst thing that has ever happened to her. Since illness can affect anybody, you cannot simply abandon someone who has met this misfortune as she calls it. She feels committed to the marriage and sees no alternative to going on. On the other hand, she has her doubts about whether to continue caregiving or not. She believes that, after all these years, she must go on even though it is difficult.

Mr T's mother expressly said that she counted on Mrs T for providing the help her son needed. Mrs T has the impression that even total commitment will not satisfy her mother-in-law. She also believes that her own situation is considered to be of secondary importance. She feels physically exhausted and has all kinds of complaints. She cannot relax anymore because she is always on duty. She would feel guilty about sharing the burden of care with others and ignoring her husband's wish. As she says: 'Sunday afternoon I go out for a walk or such thing. For the rest, I am always at home and I do everything for him'.

Reciprocity. Mrs T suffers mostly from the fact that she sacrifices so much but that her husband is not capable of showing that he is happy with her support. She hopes for some expression of gratitude and appreciation in return for all the

work she does. Mr T has not once told her that she has been a help to him. This experience has changed her and her optimism and happiness have gone.

Recently, she lost two of her supports, her brother and her father-in-law. She then could not cope anymore and her husband was admitted to a nursing home for 5 months. During that period she saw a psychologist, who helped her to see that she should spend more time by herself. When she gave up working she lost many valuable contacts with colleagues and customers. She can still rely on her daughter. It was she who told her that she was just sacrificing herself and that she had to stand up for herself and had to become harder. Mrs T sometimes resorts to medication to keep her on her feet.

Prevent an admission to a nursing home. Mr T lived in a nursing home for 5 months when his wife needed respite. Mrs T feels guilty and blames herself when he sometimes sighs that he would be better off in a nursing home.

Mrs T sometimes regrets that she gave in to her spouse about not having professional help because in so doing she closed the door on possible ways of lightening her load. She supported his decision because she was afraid that this kind of help would take away the only thing they still had in common, watching television in the evening. Now she also has to put him to bed. After the death of her family members she reached the stage where she wanted to stop, but she felt unable to have him placed in a nursing home. She mentioned lack of financial resources and being married to him for such a long time as the reasons for this.

But now I think I can't put him in a nursing home, even if his situation gets worse. I don't think I could do that, although many people are in there for the same reason. I would fall apart from feelings of guilt. If I'm really not up to it physically, then I will have to institutionalise him. That will have to decide it for me. I feel I have to push myself as far as I can go. If I can't cope physically, everyone will be able to see it and then no one will think that I just had him put away. That's a terrible thing to say, isn't it?

Two exceptional cases

Two exceptional cases did not fit this overall division between men and women in our group of participants. Mr V said that he had seen his wife change from being an active person, with an independent life and a lot of interests, into someone who is now quite housebound. He started giving care in a rather optimistic mood. He continues to provide care because he promised to try to keep his wife from being institutionalised. Mr V gave up part of his job to take care of her, and her friends and professional help do the rest. Until recently he followed the *You have to be satisfied with it* pattern, since he was able to maintain a more or less neutral view of the relationship. Although he did not consider his wife to be an equal partner anymore, he idealized her behaviour and showed compassion for how very hard it is for her.

But now, years later, he feels his caregiving has developed into an undeniable rut. This feeling has taken root since Mrs V told him on several occasions that her life has become meaningless and that she is not interested in living anymore. He can no longer ignore the strong demotivating influence that this statement has had on him and he has reached a point where doing his duty is no longer a source of satisfaction, since even his wife thinks it is useless. As his wife's emotional appeals began to intensify and the situation exceeded his limits, he developed more of an *I have to become harder and less self-sacrificing* perspective. He is now in doubt and the outcome of the situation is uncertain.

A second contrasting case is that of Mrs A who has provided care for her husband, who has MS for more than 30 years. She has a very practical and stoical attitude towards her situation and takes life as it comes. MS did not destroy their plans for the future because they had no plans together. She told us that he wanted to divorce her but that only the financial consequences prevented him from doing so. She does not care about his somewhat peculiar behaviour and has developed a *you have to be satisfied with it* perspective.

Unlike most women in the group of participants, Mrs A is not emotionally bound to her husband very much. She does not need him to say thank you and provide affection and, in some ways, there is no marital relationship left. For example, they live under the same roof but they spend most of the day in different rooms and sleep apart. Her rather neutral and distant attitude towards the relationship is similar to the male perspective of *you have to be satisfied with it*.

Discussion

In this study a main line was described that fitted the interviews with the participants in the study sample who gave care to their disabled spouses from a sense of duty. Two variants within this main line were presented. One variant fits the male reaction to caregiving and the other fits the female reaction. Men characterized by the perspective *you have to be satisfied with it*, feel obliged to give care and then become resigned to it. Women with the perspective *I have to become harder and less self-sacrificing*, as opposed to the men, do not feel compensated for the care they provide and they suffer from the burden ensuing from it. Whereas men set limits and protect their own lives, women would feel guilty if they did the same. Two participants did not fit this overall pattern. One man saw himself depleted of his energy and motivation as his wife did not want to live anymore. One woman did not corroborate the pattern since caregiving had become part of her life and she could put into perspective that her husband withdrew himself and that they lived separate lives.

So far our data support the combined results of a number of different studies that the greater burden experienced by female caregivers results from the fact that men and women have different responses to caregiving (Miller, 1990; Parker, 1993). By and large, females in Twigg and Atkin's (1994) study could be described as engulfed, whereas males adopted a more detached and

balancing mode. Based on our sample of carers who predominantly talked about duty, the link with gender seems to be amplified. This seems to indicate that when giving care from a sense of duty, women tend to respond with an engulfment mode. Engulfment then may be due especially to sensitivity to the dynamics of a problematic relationship and not from a measurable caseload as such. On the other hand, men who are mainly motivated by obligation are more likely able to set boundaries and to make space for their own interests. This is not to say that females cannot adopt a balancing mode or males an engulfment mode, but they will do so out of a different motivation to give care.

Our findings suggest that the perception of the exchange of support and help within the relationship is important for the meaning that the caregiver attaches to caregiving. Especially the women caregivers were heavily burdened by their husbands' behaviour and had more negative perceptions of the spouse than the men had. It may be the case that the responses of the female caregivers led the spouses to behave as they do and sometimes led to an escalation of their demands, forcing their wives to do things against their will, while male caregivers prevent their wives from indulging in what the caregiver sees as unacceptable behaviour. Care receivers do evaluate spouses' helping behaviour and their evaluation influences the acceptance or rejection of help and the manner in which it is accepted or refused (Bailey & Kahn, 1993; Kuijer, 2000). On the other hand, the perspectives of the caregivers might follow from the responses of the care receivers. The relationship between partners and in particular the development of the relationship through the years would therefore make an interesting focus for follow-up research (Lyons & Mead, 1995).

The experience of spouses is at least ambivalent. We found commitment to provide assistance to the spouse, but there is also normative pressure on them. Thus caregivers pose moral responsibilities to welfare agencies precisely because they cannot be assumed to pursue their own interest in a straightforward way (Twigg & Atkin, 1994). Women acting out of a sense of duty are particularly at risk of physical and psychological illnesses. For home care services, this means that while focusing on the disabled person is important, the context in which care is given is also a matter of concern. When caregiver and cared-for person are locked into a relationship that neither may wish for, questions can be raised about the adequacy of such care. This is what the independent-living movement in Britain has formulated as its spearhead: community care should be aimed at adequate provision of services for disabled people who require assistance since receiving help within personal relationships can seriously undermine these relationships and hinder independent living for both parties (Morris, 1993b).

We wish to emphasise that a rather small sample of 13 persons was used. Firstly, these spouses were chosen because they look after partners who are care-dependent for their basic needs. Secondly, the analysis was restricted to the interviews with the 13 spouses whose main motivation for caregiving was their sense of duty. It is not certain whether warmth and intimacy were entirely absent or whether it is mostly a way of expressing oneself (see also Lewis & Meredith, 1988). This limitation notwithstanding, the study addresses the

experiences of caregivers and adds to the existing knowledge about caregiving in spouse relations.

We reflected on how the interviewer characteristics, for instance our age, occupation and sex, could have affected the experiences and ideas that both male and female interviewees voiced. Weiss (1994) argues that it is difficult to anticipate what interviewer attributes will prove important to a participant and how a participant will react to them. We obviously were outsiders to the caregiving experience and to the world of men. Sometimes we found common ground in living in the same area, in being a woman and raising a child, and – one of us being a nurse – in the concerns of home health care. Some participants appreciated that they got the opportunity to talk openly to an outsider. In any case, we cannot be sure that interviewees would have emphasised different parts in their stories, mitigated their opinion or withheld answers, had they met another interviewer. However, our introduction and first questions ('What is it like for you to give care to your spouse and what concerns do you have at this moment?') was directly seized upon by the participants and set the stage for the rest of the interview. This established the idea that participants had anticipated what they wanted to share with us in the interview and that they gave a valid account of their experiences at this stage in their lives.

Finally, there is also the question of why the men in our sample felt less overburdened than the women. Why is it that men establish their limits? Why are women less capable of withdrawing from time to time? Komter's (1991) observations of the differences in the way men and women experience rights and duties are interesting in this respect. Komter's assumption that male caregivers have a vaguer experience of their duties and a more precise experience of their rights, while women experience the reverse, would seem to be true. This distinction echoes Gilligan's (1982) assumption of possible differences in the moral orientations of men and women, in the sense that an ethic of care and responsibility is more pronounced and developed in women, while an ethic of rights and justice is more pronounced in men (Gremmen, 1995).

Of course, this distinction in gender-specific orientations is a sweeping generalization. In fact, two ideal types are constructed which certainly do not apply to all women or men. This distinction in moral orientations is relevant, however, considering the existence of different male and female social values, and norms and assumptions when it comes to giving care. To put it simply, when women give care, they act in line with societal expectations. When men give care, they believe they are doing something special which deserves attention and reward.

This difference implies that a certain range of choices and options exists for men that is not available to women. The option of not actively taking care of their spouses on a day-to-day basis and of leaving care to others will, given the current cultural configuration, cause fewer feelings of guilt and entail less emotional cost for men. Opting-out, however, can entail a high emotional price for women. Facing this taxing choice implies a feeling of burden and emotional difficulty. For women, the decision to give care is almost unavoidable. This

inevitability implies that women feel that they have to be continuously available. This feeling is probably weaker among men. The males in our sample have made a more explicit choice, as it were, to take the role of caregiver upon themselves. This more explicit choice leaves the way open for them to experience greater satisfaction in caregiving and provides them with a better opportunity to withdraw from time to time.

We do not claim that men and women are always aware of these differences in assumptions and situations. It is perhaps better to speak of internalised sets of standards and values that are taken for granted to a large extent. Once again, what Gilligan has to say on this topic is interesting. She uses the metaphor of a web to describe the moral orientations of women (Wolfinger *et al.*, 1999). Women are supposed to meet moral dilemmas mainly in terms of social relationships, while men, when faced by them, tend to establish priorities and to assess the dilemma in terms of costs and benefits rather than in terms of interpersonal connections. This also implies that men may be able to maintain a certain distance from the situation they are in, while women find this more difficult. It is precisely this distance that makes men less vulnerable in the demanding situation described in this article.

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Appendix

Composition of the study group of caregivers

Participants	Sex	Age	Employment	Duration of spouse's illness	Spouse's difficulty with ADL ^a	Health and social care services
1	Female	66	Retired	37	5	District nurse
2	Female	52	Housekeeper	4	5	District nurse, housekeeping
3	Male	60	Works part-time to give care at home	13	6	District nurse, housekeeping
4	Male	48	Works full-time	8	3	District nurse, housekeeping
5	Male	53	Works part-time to give care at home	3	2	District nurse
6	Male	66	Retired	12	4	District nurse, housekeeping
7	Male	58	Stopped working to give care	20	6	District nurse, housekeeping
8	Female	48	Stopped working to give care	29	5	—
9	Male	70	Retired	23	6	District nurse, housekeeping

continued on p. 244

Appendix, continued

Participants	Sex	Age	Employment	Duration of spouse's illness	Spouse's difficulty with ADL ^a	Health and social care services
10	Female	61	Housekeeper	37	6	District nurse
11	Female	60	Housekeeper	16	6	District nurse, housekeeping
12	Male	57	Registered as disabled	15	6	District nurse, housekeeping
13	Male	75	Retired	15	5	District nurse, housekeeping

^aADL, Activities of Daily Living (bathing, dressing, transfer, toileting, continence care and feeding).

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